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BREAKING GROUND

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EDUCATION ISSUE



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Cover photos by Ned Andrew Solomon

TOP PHOTO: TEACHER, DAWN JONES

BOTTOM PHOTO: TEACHER, JERI HARRIS

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MAKING INCLUSION MEANINGFUL: LESSONS FROM SEQUATCHIE COUNTY

By Ned Andrew Solomon

An increase in student test scores. Improved student self-esteem. Better collaboration and cooperation between special education and general education teachers. And schoolwide, an enhanced sense of belonging and community for staff, students and parents. These are some of the positive—and natural—by-products of the Sequatchie County School System's nearly ten-year efforts and commitment to meaningful inclusion for students with disabilities.

Efforts that garnered the Sequatchie County School District an Award of Excellence in Inclusionary Practices from Joseph Fisher, assistant commissioner of education, and Lana Seivers, commissioner of education, on March 19, 2004. So why does this small rural county in Southeast Tennessee get it, when many of their bigger county counterparts do not?

It could be because Sequatchie is one of the fastest growing counties in the region. Or that there are only four schools in the county—one elementary, one middle, one high school plus an inclusive preschool. Or perhaps that two of the three school principals have special education degrees. Or maybe it's because the 265 members of the Sequatchie County Chamber of Commerce are Partners in Education, actively involved in the school system.

Or it might just be all of those things, plus the fact that the school board, the administration, the teachers and the parents simply want to do it, and because they believe that inclusion is not just something to be done to make sure the system is following the bare minimum requirements of the Individuals with Disabilities Education Act (IDEA) or No Child Left Behind (NCLB). It is a belief system that is underpinned by thoughtful staff hiring, ongoing and extensive staff training and development, significant investment in staff and materials, constant supervision and support from administration, and a pervasive philosophy of love and respect for all learners.

NO FLASHING SIGN

The first thing you notice when visiting a classroom in Sequatchie at the elementary, middle or high school level is that you may not notice anything at all. Chances are you won't know which students have IEPs (Individualized Education Programs) and which don't. "When you come into our schools, there's not a flashing sign that says inclusion," says Sarai Carbaugh, assistant principal at Griffith Elementary School. "You may not know unless we tell you. Some parents who were in special education when they were younger were in segregated rooms, and had very negative feelings about that. So they really appreciate this effort."

"The biggest thing I see at the high school level is taking the stigma of special ed away from these kids," adds Tommy Layne, the Sequatchie County High School principal. "Because the kids don't know who's special ed and who's not."

That lack of distinction removes barriers in some unexpected ways. "As a middle school principal, when they get pulled into the office for being in trouble, one kid may be a special ed student and one may be regular ed," says Donald Johnson. "They're getting in trouble together, so I guess they've bonded in some way."

THE CASE AGAINST "PULL OUT"

Johnny Cordell, the Sequatchie superintendent of schools, has been on the job for 11 years. That's not unusual for a county that has extremely low turnover

in staff and administration. For Mr. Cordell, including rather than excluding is just basic common sense. "When I first came on, they were pulling children out, holding them back, and expecting them to catch up," says Mr. Cordell. "I couldn't understand that."

"If you're pulling them out, they're missing out on the curriculum that's being taught," says Nancy Dennis, Sequatchie's supervisor of special education. "They have to hear what that regular ed teacher is teaching, because they'll be tested on it. We assume that any new student is going into a regular ed classroom," says Ms. Dennis. "If they cannot function there, if it's not the appropriate setting, then we back up."

Administration and faculty recognize the importance of creating a classroom experience that will represent the kind of world the students will live in when they finish high school. That is, a world peopled by persons of all abilities. In a small county like Sequatchie, most of the students who graduate from high school will either go on to college or enter the county's workforce. "The school board members realize the importance of inclusion too," says Ms. Dennis. "They look at the kids and what they have been able to do. If we graduate them, it's only helping this community. They have to fit in society. That's not going to happen if they're always pulled out and put in a little separate classroom over here."

THE NUTS AND BOLTS

It's no small thing to have all the stake-

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holders on the same page in terms of an inclusive philosophy. But how does it actually work? Well, for starters, there is a special ed teacher at each grade level, and a special ed assistant at almost every grade level. It also helps that two of the three principals are former special ed teachers. In a typical grade, there are general ed classrooms and inclusive classrooms. An inclusion classroom is where children who have a special ed certification are in a general ed classroom with general ed students, with the supports they need to succeed, including attendants for students with physical disabilities or who are deaf or hard of hearing. The most basic support in the inclusion classroom is the presence of two teachers: one general ed and one special ed.

For example, of ten 1st grade classrooms, three or four will be inclusion classrooms, with five or six students with IEPs in each room. "If you were to spread all those children over ten classrooms, it wouldn't be feasible for our special ed personnel to go in for reinforcement and support," says Ms. Dennis. "We pick children and divide them according to their needs."

Jeri Harris has been a special ed teacher in the Sequatchie school system for five years. On a typical day, she splits her time between two different 4th grade classrooms. When she and the general ed teacher are in a classroom, they are on equal footing, and share the lead teacher role equally. "We call it tag-team teaching, and the kids just eat it up," says Ms. Harris. "One of the two of us will start off the lesson, and give a recap from yesterday, and then tell them what's going to happen today. Then the other will take over. The transitions are smooth and very natural, and there's nothing like the energy and the way we work off of each other."

Which is of course music to Supervisor Dennis' ears. "The teachers have to be friends in the classroom, and they have to be a team," says Ms. Dennis. "It's not my kids or your kids or their



JOHNNY CORDELL AND NANCY DENNIS
PHOTO CREDIT: NED ANDREW SOLOMON

kids. It's our kids. That's the philosophy of this school system."

If a particular child needs help in the classroom, either teacher may come to his or her aid. "At times, there are children who still need extra help, in a small group or one-on-one, and I will pull them into the resource room if I need to," says Ms. Harris. "But that's not just for children with IEPs. It could be kids who have been out, or others that need to catch up."

There are CDC classes (or segregated classrooms) for the students with the most significant educational challenges. "We also do inclusion with those students, according to their ability level," says D.J. Johnson. "If they are capable of being included in an inclusion classroom, we will do the best we can for that child. Some go out twice a day. If there's one area they're stronger in—like math—we'll have them go to the math class with supports."

How is the determination made which class will become an inclusion classroom? "You look at your personnel, and determine who would make it the most positive experience," says Mr. Johnson. "It's not necessarily the most experienced teacher. As an administrator, you have to know your people and their personalities. Once the other teachers see it's working, you can create other inclusion classrooms. But you can doom it to failure from the beginning by choosing the wrong people."

"But we also tell teachers," continues Mr. Johnson, "if you haven't had an inclusion classroom yet, it just means you haven't been here long enough. Inclusion is here. This is what we do."

There is some resistance but not all of it comes from the general ed teachers. Mr. Johnson recalls his time as special ed teacher at the high school level. "When they began talking about inclusion, my ego was such that I felt like I could do a lot better job with those kids where I had them than they could in the regular ed classroom, because I understood them, and I could reach them. I had to work all that through in my own mind to see what the big picture was. If I was a good teacher and could help 10-12 kids in a high school science classroom, then could I also help them in a classroom with 30 kids, and maybe benefit the kids and the regular ed teacher to understand there are other ways of teaching besides, 'turn to page 57, we're doing this today.'"

Sequatchie is not resting on its laurels. Ms. Dennis wrote a grant two years ago to finance even more inclusion at the high school level. With that grant, they were able to add 15 inclusion classes at the high school level and three para-professionals. Part of the systems' success is how they decide who they will hire. "We didn't just pick anybody," explains Ms. Dennis. "We knew we needed someone for science, someone for math, and someone for English. So we looked at the backgrounds of each of the applicants. It's not random – it takes a lot of thinking to deter-

mine who needs to go where to truly benefit the kids.”

The grant will of course help, but Ms. Dennis and Mr. Cordell have a long history of investing whatever it takes to ensure successful student outcomes. “I put general purpose and IDEA money into personnel in the classrooms,” says Ms. Dennis. “I don’t care how many programs you have—million dollar programs—if you don’t have the person there to help that child, it’s not going to work. The people—and the right kind of people—make the difference with inclusion.”

AN ATTITUDE OF “WHAT CAN WE DO TO MAKE THIS WORK?”

Joanna Wicker is on the staff of the Sequatchie County School system, working in the area of curriculum and instruction. She is also the parent of a Sequatchie student, Drew Wicker, an 11th grader with muscular dystrophy, who has attended all three schools since 1st grade—in his power chair, and most recently, with his service dog, Pekoe. He has consistently been in the top ten in his class, and has always been included in general ed classes. “Coming from Alabama we were truly amazed when we first came here,” says Ms. Wicker. “We visited the school before my husband took the job here. They looked around the building and they said, ‘what do you see that your child would need?’ We pointed out difficulty getting in certain doors, or access to the cafeteria. They started putting in ramps before we ever moved here. They did everything they could.

“We came from a system in Alabama that had one attendant for every child in the school who needed one, so he was only with my son a few minutes every day. We came here and he has had a full-time attendant. It was a luxury.”

Drew is not only included in the classroom—he’s a fully participating member of the whole school community. “My son plays the drum in the band, we go to all the football games, and the dog is welcome everywhere,” says Ms. Wicker. “We go on field-trips and out-of-town conventions with the school. He goes to drive-in movies with his friends, and has a bunch of great friends in the band. He’s included in every thing you can imagine.”

Shannon Housley is teaching 1st grade this year. She has a son in the 2nd grade who has autism. “We started from the get go in preschool here,” says Ms. Housley. “He had a wonderful experience, with a 6-1 teacher/child ratio. He was in an inclusion room in kindergarten. He’s the only child at that grade level with autism. He’s broken some rules, and been dealt with like any other child. He’s a normal child, except he has autism. So we’ve always really pushed that he be treated the same as any other child. There was never a question about whether or not he be pulled out into a separate classroom.”



SHANNON HOUSLEY
PHOTO CREDIT: NED ANDREW SOLOMON

Ms. Housley has spoken with other parents at autism conferences, who relate nightmare experiences of getting their child with autism included, or adequate services provided. “We’ve never had that experience here,” says Ms. Housley. “There have been times that I’ve disagreed with something that was going on. I went and talked to them and it was fine. I don’t think it’s just because I’m a teacher. They’ve done that for all the kids here.”

IS THERE LIFE AFTER HIGH SCHOOL?

In keeping with their concern about the community at large, the Sequatchie County School administration is interested in what happens to their kids after they walk out their school doors for the last time. They have a school-to-work program—school part/work part—to get the students ready for careers. They host a career day at the high school, where almost every local business brings a display letting the students know what’s available after they graduate. They also bring in representatives from colleges and universities to speak to the students. And under Ms. Dennis’ guidance, the lead teacher in high school is conducting a survey of the students who graduated last year, to follow-up and see what those kids are up to, and whether they might need additional support with their higher ed or employment choices.

“We do job shadowing for all our kids,” says Ms. Dennis. “They go out into all these different companies, regardless of whether they have an IEP or not. And, of course, we do all the career assessments to guide them toward employment. Transition is such a big part of NCLB and I think we do a great job here. Because guess what? If we don’t produce good productive citizens at Sequatchie County High School, the community won’t have good productive employees.”

SPREADING THE GOOD WORD

Many schools have come to see why it works so well in Sequatchie County, and Ms. Dennis and her staff have done presentations and trainings around the state. “I don’t know how many school systems have come to us after we received the Award of Excellence,” says Ms. Dennis. “We’ve sat at this table and I’ve explained inclusion to them. I guess I just assumed everyone was doing this. They’re not doing this throughout the State. This is what we do for kids. This is what is right for kids. I have presented at many conferences and gone into school systems to talk to the entire staff to tell them the benefits, why we do it, and that it will work. The regular ed teachers say, ‘well I don’t know how to teach those children.’ But those children are our children. Just because they have difficulties, it doesn’t mean they’re not our kids.”

Ned Andrew Solomon is the director of Partners in Policymaking™ for the Tennessee Council on Developmental Disabilities.

FINDING THE WAY By Donna Brogden

My daughter, Rachael is experiencing a good transition plan. It wasn't always this way. Unfortunately, she wasn't able to get moving along until after graduation. The good part is that she graduated at 17 and has never looked back. I think that it takes mistakes and challenges sometimes to make us step up to the plate and hit the ball in the right direction. I have taken the mistakes that I made in the past to guide me as I work with Rachael to pursue her dreams.

We lived in a rural county while Rachael was in high school. The only option that the local VR [Vocational Rehabilitation] office wanted to put on the table was a sheltered workshop in another county. This would mean that Rachael would ride the bus for 45 minutes one way with older men. I let the school know before our exit meeting that this would not be an option. I decided to move to a much larger area after graduation so that she would have more choices with VR services.

We waited until after her 18th birthday to get the VR services going in Knox County. It was a smooth transition but it did take patience to get all of the evaluations and certifications. Rachael didn't enjoy the wait but she hung in because I promised that we would get a plan in place. Finally, in late Fall, we were ready to receive services. Rachael had a choice of training at the TRC [Tennessee Rehabilitation Center] in Smyrna or of looking for employment. To Rachael there wasn't any choice because her goal was a paycheck. So, we decided on the supported employment program.

The supported employment program was wonderful. We had a choice of three agencies and chose the Cerebral Palsy Center because it was close to our home. We had a job coach within a few days. I can't say enough for the wonderful job that she did with Rachael. It was when Rachael began exploring opportunities with the job coach that I realized the goals weren't about what I wanted but about what Rachael wanted. She wanted to work in a store as

a cashier. Since Rachael didn't have the math skills or communication ability it wasn't easy to find something that worked. Her job coach realized that Rachael wanted to be around people. So, by the first week of the new year Rachael began training to be an usher at a movie theater in the mall.

There were many things that Rachael had to learn during her training. She learned how to do the job, how to know when to be back from break and how to ride public transportation. I again have to give credit to her job coach. She worked beside her and gave her the confidence and guidance that she needed to succeed. Rachael has been with the theater for almost two years and she is a very dependable employee. She has supports and technology in place that help her to succeed.

I have realized that my daughter has a very strong opinion about what she wants. She wants to live in her own apartment and be as independent as possible. We are currently working on this by going through various programs. First, Rachael was accepted to the Self-determination Medicaid waiver. This waiver will give both Rachael and I the ability to work on the goals that will help her to obtain her dreams. It will allow us to pursue the sup-

ports and to have independence from each other. I think that this is key for her to participate in life to the fullest. Rachel wants to do all of the things that her typical peers do. This is a very exciting and important time for her to explore and build the skills that she needs for the future.

Secondly, we have begun to explore other work possibilities. We are in the process of having her VR case re-opened for further training and skills. Rachael has more to contribute to the community and so we will begin to explore how she can travel down those avenues. Self-employment is an option that we are exploring. If we choose this option, we will use a PASS plan from Social Security. We plan to fully utilize the programs that are available to help her succeed.

Rachael's transition is an ongoing journey. It will take patience and perseverance to find which direction she will follow. We will continue to navigate the path and work towards the future.

Donna Brogden is the mother of three children and is the East Tennessee Transition Facilitator for STEP, helping other families navigate the maze from high school to adulthood, and is a member of the Consumer Advisory Board for the Boling Center.



RACHAEL BROGDEN PHOTO CREDIT: DONNA BROGDEN

STATE COUNCILS ON DEVELOPMENTAL DISABILITIES MEET IN NASHVILLE

PUBLIC POLICY CONFERENCE

On November 4&5, 31 State Councils on Developmental Disabilities met in Nashville for a conference on public policy advocacy. Training for the 50 participants was provided by Brian McGuire and Mary Liz Knish of the AARP of Tennessee. Using the Western Academy of Chicago's Organizing for Social Change, processes for choosing and implementing an issue campaign were presented.

Prior to the conference, the Tennessee Council conducted a survey of State Councils to identify their most promising practices to accomplish public policy and systems change. With an amazing 89% response rate to the survey, Tennessee presented results of the survey which are being written into a report. The conference also featured panels of Council staff and members discussing various successful approaches to public policy advocacy. The Tennessee Council staff presented information on forming successful partnerships among organizations.

The conference was produced through a grant from the Administration on Developmental Disabilities received by the Tennessee Council last year. Attending the conference from

Tennessee were Steven Sheegog from Memphis, Council member and chair of Tennessee's Legislative and Public Policy Committee, William Edington, legislative and public policy coordinator, and Wanda Willis, Council executive director.

STATE COUNCIL EXECUTIVE DIRECTORS' FORUM

The Executive Directors of State Councils on Developmental Disabilities met for their first annual forum in Nashville, Tennessee on November 6&7. Thirty Council executive directors attended the two-day meeting, which followed the Public Policy Conference sponsored by the Tennessee Council on Developmental Disabilities. The meeting was convened by Eric Jacobsen, executive director of the Georgia Council on Developmental Disabilities. Council directors tackled a long list of issues, including the upcoming reauthorization the Developmental Disabilities Assistance and Bill of Rights Act, performance indicators used by Councils, the Alliance for Full Participation Summit follow-up and various other administrative and program issues facing State Councils.

Council Executive Directors rated the forum highly successful and plan to meet annually each November.

THE TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES: STATE COUNCILS MEET

THE COUNCIL'S MISSION

The Tennessee Council on Developmental Disabilities provides leadership to ensure independence, productivity, integration, and inclusion of individuals with disabilities in the community through promotion of system change.

WHAT IS THE COUNCIL?

The federal Developmental Disabilities Act created a council in each state and the five territories to provide citizens with disabilities the opportunity to improve state service systems. The Tennessee Council consists of 21 persons who have disabilities or family members with disabilities and who represent the State's nine Development Districts. The Council also includes representatives of private and State agencies that provide services or administer funding for disability-related services.

PROMOTING SYSTEM CHANGE GRANT PROGRAM

The Council promotes innovative demonstration projects through time limited grants in areas such as housing, voting, public transportation, health care, employment, and child care.

PUBLIC POLICY

The Council works with State and federal legislators and public and private policy-makers to improve the lives of persons with disabilities and their families.

LEADERSHIP INSTITUTE

Two programs bring Tennesseans with disabilities and their family members together to learn about disability issues and enhance their leadership and self-advocacy skills.

PUBLICATIONS

The Council publishes two free publications (*Breaking Ground*; *Legislative Monitor*) to keep Tennesseans informed of disability issues.

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TRANSITION PLANNING: PREPARING YOUR CHILD FOR THE FUTURE

By Ed O'Leary

Successful transition from childhood to adult life is an extraordinary challenge and achievement for any young person, especially a young adult with a disability. Family members often question what they can and should do to help.

The first step for families to remember is that your interest and concern does make a difference! Research shows that students whose families were actively involved in their education achieved greater success in their adult lives than those whose families were not.

The second step is to learn about the legal requirements for transition. The Individuals with Disabilities Education Improvement Act (IDEIA) of 2004 requires that schools prepare and assist students with disabilities for adult life. The transition provisions in IDEIA are in response to findings such as:

- A disproportionately high number of students with disabilities drop out of school.
- A disproportionately high number of adults with disabilities are unemployed.

To be engaged in school, students need to believe that the school experience is relevant to them and their future. In the middle school years, students need to be thinking about their adult lives. What kind of work might they like to do? What type of further education or training would they like to receive? Where would they like to live? What would they do for fun and recreation? Do they want to go to college, a technical trade school, or get a job? Beginning in middle school, they need to take an active part in choosing and making decisions and planning for



the courses they will be taking through their secondary years. They need to begin to understand how the courses (elective, required, and other educational experiences) will help them to achieve what it is they might want to do when they graduate. The IDEIA transition requirements outline the

school's responsibilities for designing an educational experience that will help students realize their hopes and dreams. The IDEIA transition requirements include three major concepts:

1. Help students to identify post-school goals and develop a long-range plan to realize those goals.
2. Design the secondary school experience to ensure that the student gains skills, experience, and competencies needed to pursue these goals.
3. Before leaving school, identify and connect the student and family to any needed community services, supports, or programs that they may need in order to be successful when they graduate and take the next step in life.

Specifically, the IDEIA transition provisions require the following.

By no later than the first Individualized Education Program (IEP) to be in effect when the child turns 16 years of age, there must be a comprehensive education plan, which outlines the course of study (all courses and educational experiences) that the student needs in order to support his/her long-range post-school plans. In preparation for this long-range plan, the school should provide you and your child with what courses and

educational experiences are available in middle and high school. This should include required courses as well as elective courses and educational experiences that can be created that match your child's post-school goals or interests. Additionally, if your child wants to go on for further training or to college, this type of planning, discussion and decision making should include relevant entrance/admission requirements for post-school options. For example, information on the pre-college course requirements and the implications of earning a regular high school diploma on college admission should be discussed with your child. Additionally, the school should be helping your child understand his or her disability well enough to make realistic decisions on post-school options and request any needed accommodations.

Parents can help by asking questions such as, "What classes will my son/daughter be taking in high school? How will these courses prepare him/her for further education, employment, adult living? What are the opportunities for career exploration, vocational training, and apprenticeships?" You might request that the guidance counselor join the IEP team to share information about requirements for further education. Ask how the school might help your child develop self-advocacy skills that he/she will need as an adult. Does your school offer a class in self-advocacy or self-determination? If not, ask the IEP team to explore options for addressing these issues.

Also, by no later than the first IEP to be in effect when the child turns 16 years of age, the IEP must include a plan to address your child's transition services. This is a comprehensive and coordinated plan that specifies what needs to happen, when it will be accomplished, who is involved, and the responsibility of each

party (school, child, family and the appropriate post-school services, supports, or programs). As the school, child, and family work together to develop this plan, they need to begin to identify and involve individuals from the post-school services, supports, or programs that will be critical to the child's future success. Depending on what the child wants to do and the types of services, supports or programs they may need, some examples could include: rehabilitation services; support service personnel from technical schools, community colleges or 4-year colleges; Social Security; and representatives from adult agencies. These people can and should be invited to the IEP meeting to help in the planning and assure that the services, supports, or programs are in place before your son/daughter leaves the school setting.

If the child's IEP (which includes the discussion and planning for transition services), is to be effective, then the IEP meeting should begin with the child's goals and dreams in mind. Once that is identified, every discussion and decision made in the IEP meeting should be made to support the child in achieving those goals and dreams. If transition planning does not begin with a discussion about your child's goals for adult life, show the teacher this article and ask how you can work together to make it happen. If you want additional help or information, contact the Tennessee Department of Education, Division of Special Education, at 615-741-2851 or 888-212-3162.

Dr. Ed O'Leary is a Program Specialist for Mountain Plains Regional Resource Center and consultant. He developed The Transition Outcome Project, an approach in helping districts and states meet the transition requirements and demonstrate improvement and results, which is now operating in over 25 states/regions and over 1,500 districts across the country.

Q & A WITH JANE WINSTEAD, STATE DIRECTOR OF TRANSITION SERVICES

Jane Winstead has been working with students with disabilities since 1981, first as a speech therapist, and later as a high school resource teacher. In 1990, Winstead was employed in a small rural school system when IDEA was reauthorized and included the requirement that each eligible student have an individualized transition plan (ITP). According to Ms. Winstead, "Developing transition plans and working with students in the community enabled me to see potential and success that led to increased confidence and self-esteem in students who had not necessarily had success in the classroom."



Breaking Ground: Transition is such a big buzzword word these days, and can mean so many things to so many people. Basically, we'd like to know what "transition" means to you—and how it applies most closely to the work you've been doing and will be doing.

Jane Winstead: Secondary transition is leaving the familiar education environment and entering an unfamiliar place called adulthood. In adulthood, there is no entitlement to services as in public education and IDEA. Services depend upon eligibility and available funding.

My challenge in this position is to collaborate with other agencies at the state level to strengthen policies and practices that promote a successful transition from high school to independent living, employment or further education while working to strengthen local capacity to deliver effective transition services to students and their families. Reliable data must be collected, analyzed and used to drive improvement efforts at the school district and state level.

Data will be collected through a post-school outcomes survey to determine the percentage of students with disabilities who are employed, attending institutes of higher education, receiving further training and living independently. Additionally, the compliance monitoring process and the Transition Outcomes Project will collect data on how well IEPs are meeting the transition requirements of the Individuals with Disabilities Education Improvement Act (IDEIA).

BG: What are some of your current transition activities?

JW: I am conducting various workshops across the State. I'm also available to speak to groups interested in secondary transition and to conduct teacher workshops on a limited basis. The Tennessee Connections Transition Manual is under review and will be revised to align with the new IDEIA Regulations. I'm conducting meetings with agencies and entities interested in youth in transition and adult services agencies that may provide adult services to discuss ways we can work together to promote seamless transitions for students with disabilities in Tennessee. I am also working on revising or writing technical assistance publications for parents, students, agency representatives, and educators.

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PUBLIC REVIEW OF COUNCIL'S NEW FIVE YEAR STATE PLAN SOUGHT By Alicia Cone, Ph.D.

Thank you for the survey responses received from many Breaking Ground readers. Those responses assisted the Council in completing a comprehensive review of the Tennessee disability service system. After that review was completed, a number of issues were identified that need to be addressed in order to improve people's access to and the availability of consumer-driven, consumer-directed community based services and supports.

Those identified needs were turned into the goals and objectives the Council will pursue over the next five years, beginning in August 2006. Since so many people were willing to provide Public Input into the plan, the Council again is asking for assistance by entering into a period of Public Review. In the remainder of this article, portions of the new State Plan are summarized. Council would appreciate any feedback offered from the *Breaking Ground* readers.

Additionally, the Council is providing copies of the complete State Plan at the locations and on the Web sites listed in the table on this page so that any member of the public who wishes to may review it and provide the Council with comments.

Alternative formats will be made available upon request. Mailed copies also are available upon request. For an alternate format, a mailed copy, or questions about the State Plan, please contact Alicia Cone at alicia.cone@state.tn.us, or call Alicia at 615-253-1105.

All comments need to be submitted by February 28, 2006.

SUMMARY OF THE STATE PLAN

The two most important economic and social factors currently affecting Tennessee seem to be the unemployment rate and the poverty rate. In June 2005, Tennessee's unemployment rate was 6.0%. Although employment grew by 3,800 jobs, the labor force was 2,878,800, and 173,800 of that total labor force were unemployed. Of Tennesseans with disabilities, 53.2% are employed. However, the good news is that predictors indicate that Tennessee will enjoy lower rates of unemployment than the nation over the next several years.

New Census data released in August 2005 showed a slight increase in the poverty levels in Tennessee, from 14.4% in 2002 to 15% in 2004. While more people had the opportunity to work, their pay did not keep up with inflation. It is estimated that 14.5% of families with family members with disabilities live in poverty in Tennessee.

In reviewing the service system for people with disabilities, the following issues were highlighted as barriers to adequate, consumer-driven and -directed, community based services and supports:

1. Provider capacity for home and community based services continues to be an issue. It is difficult to find and keep quality, trained and energized direct support professionals. Community services remain out of reach for many Tennesseans with disabilities, especially Tennesseans with developmental disabilities other than mental retardation (MR) and acquired disabilities.
2. A system of long-term care in the community has not been adequately established in Tennessee. In 2004, Tennessee ranked 49th among all states in comparison of expenditures, with 82.7% going to institutions versus 17.3% for community services. For older persons and people with physical disabilities (this excludes people with MR or Developmental Disabilities), Tennessee ranked 50th in offering non-institutional alternatives to nursing home care.
3. Health care was identified as a significant issue due to the proposed changes in TennCare coverage and the resulting loss of insurance coverage and benefits. It is interesting to note that in 2005 Tennessee was one of eight states to register a significant increase in the percent of people without health insurance coverage, from 1.7% to 13.7%. This does not include the recent TennCare changes.
4. The two significant issues in the area of employment of Tennesseans with disabilities are that the Division of Rehabilitation Services is under an order of selection, and that the Career Centers lack capacity to directly serve people with disabilities.

AGENCY/PROVIDER	CONTACT INFORMATION
COUNCIL ON DEVELOPMENTAL DISABILITIES, NASHVILLE	ALICIA CONE, 615-253-1105, THE STATE PLAN IS ALSO AVAILABLE ON THE COUNCIL'S WEB SITE. THE ADDRESS IS WWW.STATE.TN.US/CDD .
DISABILITY LAW AND ADVOCACY CENTER (FORMERLY, TENNESSEE PROTECTION AND ADVOCACY, INC.), MEMPHIS OFFICE	ANDREA JOHNSON, 901-458-6013
DISABILITY LAW AND ADVOCACY CENTER, KNOXVILLE OFFICE	PEGGY DEVAULT, 865-689-9020, EXT. 10
BOLING CENTER FOR DEVELOPMENTAL DISABILITIES, MEMPHIS	ELIZABETH BISHOP, 901-448-3127, A COPY OF THE STATE PLAN WILL ALSO BE POSTED ON THE BOLING CENTER WEB SITE. THE LINK MAY BE ACCESSED AT WWW.UTMEM.EDU/BCDD . PLEASE GO TO THE BOLING CENTER'S HOME PAGE, AND SCROLL DOWN TO THE SECTION TITLED ITEMS OF SPECIAL INTEREST.
UNIVERSITY OF TENNESSEE CENTER ON DISABILITY AND EMPLOYMENT, KNOXVILLE	KIM RUTHERFORD, 865-974-9400
VANDERBILT KENNEDY OUTREACH CENTER, TENNESSEE DISABILITY INFORMATION AND REFERRAL OFFICE	THE PLAN WILL BE AVAILABLE THROUGH A LINK FROM THE TENNESSEE DISABILITY PATHFINDER WEB SITE. THE WEB SITE CAN BE ACCESSED AT WWW.FAMILYPATHFINDER.ORG .

5. In the area of housing, Tennesseans with disabilities continue to be "priced out" of the market. In Tennessee, from 2000 to 2002, growth in SSI (Sublimental Security Income) monthly payments was at 6%, while growth in one-bedroom FMR (Fair Market Rate) was at 7%. In other words, cost of living adjustments in SSI benefits in Tennessee did not keep pace with the increasing cost of rental housing.

6. As many would suspect, transportation again is listed as a significant system barrier for people with disabilities.

An issue that became apparent during this review is the lack of and need for a centralized disability policy in Tennessee. Disability services in Tennessee are complex, cross State agencies and are further complicated by various funding streams with different eligibility requirements and program purposes. There is no established, centralized State disability policy or organizational structure to promote the development of consistent disability policy and unify multiple programs and services. The result is inconsistent and frequently conflicting program policies and services. Not only are citizens confused by different approaches, eligibility standards, and scope of services across departments, but State departments

are confused as well, and ill-informed about responsibilities of the State in serving citizens who have a disability. This lack of State disability policy and coordination of programs and services has resulted in the following challenges and problems: lack of progressive policy regarding long term care, bias toward congregate and institutional services, disparate use of resources, unserved and underserved groups, waiting lists, litigation used to resolve lack of access to services and to address civil rights violations, inefficient use of State and federal resources, and fragmentation of services.

In many cases, stakeholder comments offer the best evaluation of a system of supports.

Here are a handful of comments shared in the surveys regarding what is not working in the system:

1. No funding for DD services
2. Money needs to follow the person
3. People need to have real choices
4. The medical model of services is not working
5. People are not moving out of nursing homes
6. Need personal assistance services
7. No affordable in-home care services
8. No long term care in Tennessee
9. Employment opportunities
10. Affordable housing

STAKEHOLDER COMMENTS REGARDING IMPROVING THE SYSTEM INCLUDE:

1. Build the capacity of the service system
2. More transportation options are needed, especially for people with physical disabilities
3. Meaningful work in the community
4. Greater access to affordable homes
5. Public thinking about disability has to change
6. More opportunities for people with disabilities to have and build relationships
7. In-home care for people with disabilities
8. Money follows the person
9. Offer recreational programs that are not segregated
10. Promote education of doctors regarding disability issues
11. Fund DD services
12. Create a long term care delivery system

FOOD FOR THOUGHT: There are over 20,000 people with disabilities on four different waiting lists for various services and supports offered by the Tennessee disability service system. That point alone sums up the state of services for Tennesseans who have a disability.

The Council has developed goals in seven of nine Federal areas of emphasis.

AREA OF EMPHASIS	GOAL
EMPLOYMENT	INCREASE EMPLOYMENT OPPORTUNITIES FOR TENNESSEANS WITH DISABILITIES THROUGH ALL MECHANISMS AVAILABLE.
EDUCATION	INCREASE TENNESSEE'S CAPACITY TO FULLY IMPLEMENT IDEA 2004 AND TO MAXIMIZE THE LIFE-LONG EDUCATIONAL OPPORTUNITIES OF PEOPLE WITH DISABILITIES.
HOUSING	INCREASE ACCESS TO SAFE, AFFORDABLE AND ACCESSIBLE HOMES IN THEIR COMMUNITIES FOR TENNESSEANS WITH DISABILITIES.
HEALTH	PROMOTE COMMUNITY BASED ACCESS TO AND USE OF THE HEALTH, DENTAL, AND MENTAL HEALTH SERVICES NEEDED BY TENNESSEANS OF ALL AGES, PROVIDED IN THE MOST ACCESSIBLE SETTING.
TRANSPORTATION	INCREASE ACCESS FOR TENNESSEANS WITH DISABILITIES TO PUBLIC AND PRIVATE TRANSPORTATION SYSTEMS THAT ARE AFFORDABLE AND ACCESSIBLE, AND RESULT IN PEOPLE BEING ABLE TO TRAVEL WHEN AND WHERE THEY DESIRE.
QUALITY ASSURANCE	DEVELOP AND ENHANCE LEADERSHIP AND SELF-ADVOCACY SKILLS OF TENNESSEANS WITH DISABILITIES AND THEIR FAMILIES TO DIRECT THE SERVICES AND SUPPORTS THEY RECEIVE. SUPPORT AND FACILITATE VOTER EDUCATION AND REGISTRATION INITIATIVES FOR TENNESSEANS WITH DISABILITIES.
FORMAL AND INFORMAL COMMUNITY SUPPORTS	PROMOTE PUBLIC POLICIES AND PRACTICES THAT INCREASE HOME AND COMMUNITY-BASED SUPPORTS IN TENNESSEE. INCREASE PUBLIC AWARENESS, OUTREACH ACTIVITIES, AND INFORMATION AVAILABLE ABOUT DISABILITY ISSUES AND COMMUNITY SERVICES THROUGH COORDINATED AND COLLABORATIVE DISSEMINATION OF INFORMATION.

In closing, after the period of public review, the feedback will be reviewed and changes to the State Plan will be made as needed. At its March Council meeting, the Council members will have another time to discuss the new State Plan, and then approve it for submission to the Administration on Developmental Disabilities (ADD). The plan is then electronically entered and submitted to the ADD no later than August 15, 2006. The State Plan is reviewed and modified annually as needed.

TENNESSEE SPOTLIGHT

PROJECT CONEXIÓN RECEIVES AWARD

PROJECT CONEXIÓN, a joint program of the Vanderbilt Kennedy Center and Tennessee Council on Developmental Disabilities, is an information and assistance program housed at Nashville's Woodbine Community Center. Its purpose is to assist underserved Hispanic individuals with disabilities and their families by increasing their knowledge of available resources and community support. On October 18th, Project Conexión received one of six Vanderbilt Affirmative Action and Diversity Initiative awards. Led by the Opportunity Development Center, the awards recognize groups and individuals from across the university for their efforts to actively support and promote diversity in campus life.

WEST TENNESSEE'S IMAGINE THE POSSIBILITIES CONFERENCE A HUGE SUCCESS

Twenty-eight self-advocates, most with Down syndrome, recently attended an "Imagine the PossABILITIES" Conference at Germantown United Methodist Church. A communitywide dinner the same day drew a crowd of more than 250. After a moving keynote speech by national speaker, Karen Gaffney, participants attended workshops on a variety of topics, including fitness and health. With the help of numerous folks, the Conference was coordinated by Jawanda Mast, Partners graduate and President of the Down Syndrome Association of the Mid-South.

JONATHAN MCGEE NAMED HONORARY MEMBER OF KNIGHTS OF COLUMBUS

Holy Family Catholic Church in Seymour recently made **JONATHAN MCGEE**, the son of Partners graduate Kathy McGee, an honorary member of the Knights of Columbus. The Knights were honoring the Bishop's deceased brother George, who had Down syndrome. They renamed their Council in George's name, with a mission to help and support those with disabilities, especially Down syndrome. Mr. McGee also was an altar server with Bishop Joseph Kurtz for a special mass on August 28th, and with Father Ragan Shriver in October for an "Inclusion Mass" in Knoxville. If that weren't enough, Mr. McGee walked a one-mile course in the Run for Ed(ucation) in Blount County, following a recovery from two hip surgeries.

STEVEN SHEEGOG II IS RUNNING MILES AROUND MEMPHIS

Council member and Partners graduate Steve Sheegog is proud to report that his son, Steven II, is racking up quite a few athletic accomplishments. Mr. Sheegog II, who has an autism spectrum disorder, tried out and made the East High Outdoor Track Team in his sophomore year, ran in the 1,500 and 800 meter runs, and helped his track team win the city championship. In his junior year, Mr. Sheegog made the Cross-Country team. This

past summer Mr. Sheegog joined the Blues City Runners, AAU Track club, and ran in the 1500, 800 and 4x 800 meter relay, later qualifying for the regional meet in Charlotte, North Carolina. Merry Adams, Radio Personality

2005-06 Partners participant **MERRY ADAMS** took to the airwaves on Radio Free Nashville, 98.9, at the end of October, to promote the Choices for Care campaign and to discuss the current state of health care in Tennessee. Campaign organizers hope to communicate the message that Tennesseans deserve a long-term care system that provides real choices when seeking support in the community. Ms. Adams is the Choices for Care convener for the Middle Tennessee area.

PAM BRYAN ELECTED BIAT VICE-PRESIDENT

2005 Partners graduate **PAM BRYAN** was elected the Vice-President of the Brain Injury Association of Tennessee. Her term will begin in January, 2006. Ms. Bryan's son, John, is a brain injury survivor, and Ms. Bryan has been extremely active in several BIAT initiatives and other disability-related organizations, including the Epilepsy Foundation and Access Nashville.

JOHN T. FARLEY HONORED BY COMMUNITY ORGANIZATION

The 10th Annual Benefit and Awards Gala of the Mid-South Arc on October 15th recognized many individuals and agencies that are active in advocacy and supporting persons with disabilities. The final award of the evening went to John T. Farley, a senior at Germantown High School, Company D dancer, Tennessee Youth Leadership Forum graduate, and son of Partners graduate, Brenda Farley. Mr. Farley received the 2005 Empowerment Award, which goes to an outstanding person who overcomes challenges and, through leadership and positive attitude, empowers others to achieve their goals.

YOU'RE INVITED TO TAKE PART IN RESEARCH

The Vanderbilt Kennedy Center welcomes the participation of children and adults, with and without disabilities, in research studies. In some studies, free services are provided that may directly benefit you or a family member. In other studies, you will have the satisfaction of contributing to knowledge of development or education. Some studies pay participants a modest amount for their time. StudyFinder is a Web-based tool to identify Vanderbilt Kennedy Center projects seeking participants; see kc.vanderbilt.edu/studyfinder/ or call (615) 936-0448. The Vanderbilt Kennedy Center is a national center for research on development and disabilities and a national Center for Excellence on Developmental Disabilities Research, Education and Service.

CHECK US OUT ON THE WEB AT: www.breakingground.org

A STORM OF CARING: TENNESSEE'S DISABILITY COMMUNITY RESPONDS TO HURRICANE KATRINA

By Melissa Fortson

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THE TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES: HURRICANE KATRINA

The damage done by Hurricane Katrina and its storm surge, including the flooding of New Orleans, made it the costliest and most destructive natural disaster in this country's history. While the disaster significantly affected each of the estimated million-plus evacuees, Katrina evacuees with disabilities faced additional challenges. In the rush to evacuate, people with disabilities were often forced to leave behind wheelchairs, walkers, and other equipment. Those seeking shelter in Tennessee faced separation from their homes, caregivers, healthcare, and other supports. However, the Tennessee disability community moved quickly to address these needs, ensuring that evacuees received the supports they needed to continue to live independently. The accounts of five service providers—and the people they helped—demonstrate the strength and unity of the disability community's response in Tennessee.

Memphis's Boling Center for Developmental Disabilities (BCDD), a University Center for Excellence in Developmental Disabilities (UCEDD) administered by the University of Tennessee Health Science Center, compiled an extensive collection of hurricane-related resources. These resources, available on the BCDD Website, included information about local shelter, healthcare, and aging services, as well as links to local media outlets and relief organizations. "Tips for First Responders," an 11-page field guide on how to best assist persons with disabilities, was also made available via the Boling Center site. The provision of these resources exemplifies the Center's mission of supporting children and adults with developmental disabilities and their families.

Down the road from Memphis, a unique partnership led to an "unforgettable" experience for evacuees in Jackson. Katrina Aid & Relief for Evacuees (K.A.R.E.), a local disaster group

assisting FEMA and the American Red Cross, was introduced to the Jackson Center for Independent Living (JCIL) by the director of the local Red Cross chapter. K.A.R.E. needed an office from which to assist evacuees. JCIL agreed to provide office space, and K.A.R.E. referred individuals with disabilities to JCIL.

JCIL's first referral involved a person who uses a wheelchair who needed transportation to a healthcare facility. JCIL arranged for the evacuee's transportation and also provided the following: a toilet seat extension for a person recovering from hip replacement, a telephone alert strobe light for an evacuee with hearing loss, a walker, and a set of forearm crutches. The agency also referred an evacuee with post-polio syndrome to a physician who was able to assist him in obtaining a power wheelchair, an item he had not been able to obtain in Louisiana. "We were fortunate enough to be able to provide assistance to all those referred to us," said Phillip Merrell, JCIL's Coordinator for Independent Living. "Thanks to the efforts of K.A.R.E., the Red Cross, Jackson Transit Authority, and JCIL, some of the evacuees will never forget Jackson, Tennessee."

It's safe to say that 120 people (and one dog) will never forget Tennessee, either. On Thursday, September 1st, the Division of Mental Retardation Services (DMRS) learned that 80 staff and 40 service recipients of two Louisiana agencies serving persons with mental retardation had fled New Orleans and were staying at Fall Creek Falls State Park while looking for a home. Quickly, DMRS went into action, exploring options for offering assistance and dispatching an intake team to the park that afternoon. It was decided that Clover Bottom Developmental Center was the best place for the agencies, Crossroads of Louisiana, Inc. and Hood Management Group, and the people they were serving.

After preparations were complete, the Louisiana evacuees arrived at Clover Bottom on Tuesday, September 6th. The DMRS guests are housed in several buildings, with the gymnasium available for day programs. While the plan calls for the Louisiana agencies to remain self-sufficient, DMRS staff is providing assistance, including arrangements for transportation and relief staffing. "This is a difficult time for our guests, having left home, not knowing the status of their lives there," said DMRS Deputy Commissioner Stephen H. Norris in a prepared statement. "Everyone at DMRS will work together, ramping up our efforts to make this the best possible experience for them." DMRS will likely serve as hosts into 2006.

Some evacuees had difficulty finding resources in the wake of Hurricane Katrina. In the days after the storm, Tennessee Disability Pathfinder, a statewide, bilingual information and referral service for the disability community, received calls from evacuees seeking information and access to services. "Evacuees contacted us needing services such as specialized equipment, especially wheelchairs, adult day care, and special education services," said Carole Moore-Slater, Pathfinder director. To assist evacuees, their families, and service providers, Pathfinder created a Web-based collection of resources in the areas of emergency management, education, employment, financial assistance, healthcare, insurance, long-term care, shelter, Social Security, transportation, and more. The hurricane resources page enabled the Pathfinder staff to organize the vast amounts of information they were receiving in a way that was accessible to themselves, professionals, and families.

The Memphis Emergency Management Agency and The Tennessean agreed; emergency management officials listed Pathfinder as a resource in their daily briefings and the

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RECENT DEVELOPMENTS IN TRANSITION SCHOOL TO WORK by Cindy Gardner

Recently, there have been changes in State and Federal law that will affect young adults with disabilities as they leave public school and enter adulthood. This article will attempt to explain some of those changes.

First, the Individuals with Disabilities Education Act (IDEA) was amended in 2004 and renamed the Individuals with Disabilities Education Improvement Act (IDEIA). Transition School to Work is one of the areas where an improvement appears to be the true aim of Congress in their revisions. For instance, the stated purpose of the IDEIA has added "further education" for emphasis after special education:

"to ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living;" (20 USC §1400(d)).

Another improvement for students with disabilities comes in the more clearly defined requirements for the Individualized Education Programs (IEP). As opposed to merely "a statement of needed transition services," we now have specific instructions for the IEP team:

"Beginning not later than the first IEP to be in effect when the child is 16, and updated annually thereafter –

- (AA) APPROPRIATE MEASURABLE SECONDARY GOALS BASED UPON AGE APPROPRIATE TRANSITION ASSESSMENTS RELATED TO TRAINING, EDUCATION, EMPLOYMENT, AND, WHERE APPROPRIATE INDEPENDENT LIVING SKILLS;
- (BB) THE TRANSITION SERVICES (INCLUDING COURSES OF STUDY) NEEDED TO ASSIST THE CHILD IN REACHING THOSE GOALS; AND
- (CC) BEGINNING NOT LATER THAN 1 YEAR BEFORE THE CHILD REACHES THE AGE OF MAJORITY UNDER STATE LAW, A STATEMENT THAT THE CHILD HAS BEEN INFORMED OF THE CHILD'S RIGHTS UNDER THIS TITLE, IF ANY, THAT WILL TRANSFER TO THE CHILD ON REACHING THE AGE OF MAJORITY..." (34 CFR § 300.320).

In preparing for the IEP meetings for a child 16 years of age, parents must be ready to discuss (or better yet, prepare their child to discuss) transition assessments and the child's post-school goals, taking into account their needs, strengths, preferences and interests. Not only must the child be invited to the IEP meetings, but any other agency from which services will be required (now or in the future) must also be invited. No requirement exists for the school system to ensure other agency's attendance. They are, however, required to invite the other agency and if the other agency fails to attend, the school system must reconvene the IEP meeting and discuss how they (the

school system) will provide the service that the absentee agency could/should have provided.

Parents should also familiarize themselves with the Tennessee Interagency Agreement signed November 1, 2000, which explains the responsibilities of various agencies in providing seamless transition services to children with disabilities. As one example, the Division of Rehabilitation Services (DRS) is required, under this agreement, to make available "to the extent possible" a vocational rehabilitation counselor to participate in IEP Team meetings when requested by the LEA (Local Educational Agency). In addition, DRS is to begin to help coordinate transition services for high school students with disabilities who meet DRS eligibility criteria, 12-18 months prior to their exit from school to assist them in gaining employment, including the assessment and any job preparation services in the student's IEP. At the very least, the student should have a developed IPE (Individualized Plan for Employment) prior to his/her exiting from public school, if the student is eligible for DRS services.

Another agency which has signed the Interagency Agreement is the Tennessee Division of Mental Retardation Services (DMRS). Currently operating under a settlement agreement for their "waiting list," DMRS is attempting to provide Home and Community Based Waiver Services (HCBS) to eligible individuals in a more timely fashion. Under the Interagency Agreement as part of the IEP Team process, the LEA should notify DMRS when it believes a child is eligible and may benefit from DMRS services and supports. The LEA shall be responsible for inviting a DMRS representative to a child's IEP Team meeting to facilitate planning for the child's transition from school services to adult services. Parents also should familiarize themselves with the Independent Services Coordinators in their area and the options for post-school services for their child.

Congress also is currently considering changes to the Rehabilitation Act that would require more participation from Vocational Rehabilitation (VR) agencies with transition-aged youth. As part of the Workforce Investment Act reauthorization currently being considered by the Senate H.E.L.P. Committee, the "new" Rehab Act appears to require VR agencies to not only participate in IEP meetings, but also: provide vocational guidance, career exploration services, job search skills, strategies and technical assistance to students with disabilities; support the provision of training and technical assistance to State and local educational agency and designated State agency personnel responsible for the planning and provision of services to students with disabilities; and support outreach activities to students with disabilities who are eligible for, and need, services.

The unemployment rate for individuals with disabilities in 1990 (when the ADA was passed) was approximately 70%. Fifteen years later, the unemployment rate still hovers around that same amount. Transition-aged youth with disabilities represent the greatest hope this nation has for reducing that figure and Congress appears cognizant of that hope.

The Social Security Administration also offers work incentives for transition-aged youth. The Student Earned Income Exclusion enables a student receiving SSI to "try out" working while they are in school without the concern of losing benefits. The Plan for Achieving Self Support allows a young person to set aside income or resources to be used to achieve specific work goals, even including owning his or her own business. For more information on SSA work incentives, contact a Benefits Specialist at 1-888-839-5333.

Finally, parents must be prepared for everything that may occur when their child turns age 18. If your child is receiving SSI or SSDI, for example, they will undergo a redetermination process at age 18 that could affect their future eligibility. At the same time, your child may become eligible for the Ticket to Work and Self-Sufficiency Program through the Social Security Administration. Additionally, in Tennessee, there is currently no mechanism for a parent to be allowed to participate in IEP meetings for their children over 18. Under the IDEIA, all rights formerly associated with the parent will transfer to the child, even though the child may stay in special education until the year in which they turn 22. Most school systems recognize that parents are an important part

of the IEP for this age group, and nothing prohibits them from inviting the parents, but technically the student can decide that the parent should not be a part of the IEP team and their wish will prevail. Like it or not, your child becomes an adult under the law at age 18, regardless of their physical or mental disability, judgment, or even maturity level. They can decide to quit school, hop on a bus to California and join a Polka band. Absent a Conservatorship, of course, and except for your "influence" over them, there is nothing you can do to stop them.

Parents can, however, influence the IEP process, and therefore their child's future, by becoming actively involved in their child's future planning, long before age 18. Make sure the focus remains on all the skills, services, activities, living arrangements, jobs and even recreational activities that your child will need or hope to experience post-school. Make sure your child is able to advocate for themselves to their maximum ability, since you will not always be around to advocate for them. If another agency will be picking up where the school system left off, DO NOT WAIT until your child exits school to find out everything you can about those services. Do the work now for your child's future. As The Dalai Lama says, "Happiness is not something ready made. It comes from your own actions." The actions you are willing to take now can ensure your child's future happiness.

Cindy Gardner is an attorney with the Disability Law & Advocacy Center of Tennessee.

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Nashville-area newspaper included Pathfinder in an article spotlighting local efforts to assist hurricane evacuees. Tennessee Disability Pathfinder is a program of the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy Center for Research on Human Development, a University Center for Excellence in Developmental Disabilities (UCEDD).

Deana Claiborne, executive director of United Cerebral Palsy of Middle Tennessee (UCP), notes that within 24 hours of the evacuation of New Orleans, she made contact with the New Orleans UCP affiliate and initiated help for people evacuating to Tennessee. "The first evacuees included one direct support professional and a lady with Down syndrome

who was in her care. We provided emergency financial assistance and information about housing, employment options, and resources in the Middle Tennessee area," said Ms. Claiborne. In addition to providing durable medical equipment to evacuees in Tennessee, the affiliate also partnered with the Middle Tennessee Medical Reserve Corps to send a truckload of equipment to the hurricane ravaged areas. Along with United Cerebral Palsy of the Mid-South, the chapter established a payroll deduction plan to allow its employees to voluntarily deduct a portion of their paycheck to help cover payroll costs of the sister affiliate in New Orleans. In a letter to her fellow UCP Affiliate Executives, Ms. Claiborne wrote: "100% of our employees have opted in to help—and we all feel good about doing

this because we know the best way to help people with disabilities in crisis is to keep trained and knowledgeable professionals in the field for the long haul." Through these efforts, UCP continued to advance the independence, productivity and full citizenship of people with disabilities, even in the face of natural disaster.

Tennessee's disability community has mobilized to assist with the response to Hurricane Katrina. When confronted with natural disaster, the people of Tennessee rose to the challenge, making the long recovery process just a bit easier for the evacuees with disabilities who crossed their paths.

Melissa Fortson is disability resource specialist with Tennessee Disability Pathfinder at the Vanderbilt Kennedy Family Outreach Center.

"BECAUSE WORK IS SO IMPORTANT!"

By Phil Schoggen, Ph.D.

That's the main reason Andrea Cooper left her full time job as legal counsel for a manufacturer of power wheel chairs to take a new position as Assistant Commissioner, Division of Rehabilitation Services, (DRS) Department of Human Services. The mission of this office is to help citizens of Tennessee with disabilities find successful employment. "To me, successful employment is doing real work," said Ms. Ms. Cooper, "providing a service that somebody needs, or making a product that somebody needs, doing it in an integrated setting, doing it for a fair wage, and doing it on a non-tempo - rary basis."

Having herself experienced a serious spinal cord injury several years ago which left her paraplegic, Ms. Cooper was a client of rehabilitation services. She now uses a power wheelchair and drives a van with adaptive equipment. She believes that this experience—seeing places where her own rehabilitation process could have been improved—equips her to do a better job in her new position. Yet Ms. Cooper is quick to point out that she must reach well beyond her own experience with vocational rehabilitation because each disability is unique. Even people with the same disability have very different circumstances, and these circumstances largely determine what the disability means to the person.

Ms. Cooper was impressed with what she learned in going back to work herself, and how many people it took to get her there.

"It certainly wasn't one case manager who could put me back to work. Definitely was an interdisciplinary effort from friends, agencies, directors, people in the disability community, people in the business community. And I really wanted to be able to coordinate that kind of support for other people," she said.

Ms. Cooper believes she has had a very good outcome in going back to work—and she wants that for every person with a disability. She feels that there is a real advantage for her when she visits a worksite in her power chair to look the manager of the worksite directly in the eye, as she has done, and say, "This worksite needs to be accessible to wheelchairs."

For years, as an unpaid volunteer, Ms. Cooper has served as Chairperson of the Tennessee Council on Developmental Disabilities. She feels that this experience also contributed enormously to her understanding of disabilities. "It gave me exposure to different kinds of disabilities," said Ms. Cooper. "It was the first time I really had a chance to talk to parents of children with disabilities...and learn what parents want for their children with disabilities. Most of the time they would say, 'I want my child to have friends, and I want my child to be a part of society.' To me, a natural extension of that, or a natural means to achieve that, is in the workplace."

"The Council on Developmental Disabilities provides opportunities for us in the Division of Rehabilitation Services to start some pilot projects, to think outside the box. The Council is uniquely positioned to have access to many persons with various kinds of different disabilities statewide and that, to me, is a goldmine of information that, if the Division of Rehabilitation Services isn't capitalizing on now, they really need to be doing that."

The special appeal to Ms. Cooper of this job with DRS is the opportunity to con-

tribute to public service. Here she has a chance to make decisions and organize the process that affects many people at one time. Her legal training and her extensive work as a lawyer taught her how to ask the hard questions, and keep asking them until she got the answer she was seeking, or was satisfied that the person really did not know. Her work for the private corporation gave her numerous contacts with clients with disabilities as she learned about the philosophy of customer service. It also taught her about what a complaint is. "Now I explain to our supervisors and our counselors that a complaint is nothing more than an expectation that has not been met," said Ms. Cooper.

Six directors of other State offices report to Ms. Cooper: Tennessee Council for the Deaf and Hard of Hearing; Tennessee Technology Access Project; Vocational Rehabilitation; Tennessee Rehabilitation Center; Blind Services; and Disability Determination Services. Some of these entities use State funds and some are federally funded, but all involve considerable intergovernmental cooperation. Ms. Cooper says that this is made more difficult by the fact that the State and federal governments are on different fiscal years. The vocational rehabilitation programs are 21.3% state funded with



the balance coming from the federal government. "That's a lot of numbers for an English major!" remarked Ms. Cooper.

One of Ms. Cooper's most important goals is making sure that the service they provide in DRS is top notch. "We have a lot of questions about what is serving the client, and my goal is to help people understand what I am thinking of when we serve a client," said Ms. Cooper. "We are a source of information for that client. We can refer them to other places. We can provide guidance, we provide interest exploration—these are all things that need to happen in the process rather than just writing a check for services. Too often, people don't see our capacity to provide information as well as services."

Ms. Cooper speaks with pride about a new initiative that DRS is involved in: Project Opportunity. "It is an agreement with Vanderbilt Children's Hospital, a pilot program modeled after Cincinnati hospital," she said. "The Division now has six students with disabilities there in their last year of high school who are learning about various jobs in the hospital. Because the hospital provides such an interesting environment, there are many different tasks that they can learn about. It's great that Vanderbilt has been open to doing this. It is a great example of collaboration with a private business."

Breaking Ground salutes Andrea Ms. Cooper on her new venture, and her efforts to help Tennesseans with disabilities find successful employment. Phil Schoggen is a Professor Emeritus at Cornell University, and resides in Nashville.

Phil Schoggen is a Professor Emeritus at Cornell University, and resides in Nashville.

A PARENT'S PERSPECTIVE ON IDEA 2004 By Holly Lu Conant-Rees

I'm the mom of a young man, Samuel, who, at 22, is a special education survivor. He owns Sam's Lawn Service, and is unrepentantly snobbish in differentiating between lawncare professionals like himself, and amateurs, which term probably describes everyone else in this room.

I learned not long ago that the word "amateur" is in fact not a slur but taken literally, means "one who loves"—someone who is in it for the love rather than the money, prestige, status. So I'm here today as an amateur—which means that I have shallow pockets, but my comments rise out of deep love, respect and intimate involvement with the community of children and youth with disabilities and their families.

It is not shocking news that many of us in the advocacy community believe that the 2004 reauthorization of IDEA substantively erodes the rights, protections and procedural safeguards available to students with disabilities and their families. I'm not alone in finding the label "IDEA Improvement Act" both inaccurate and unpalatable.

In preparing for the first round of public hearings, we pored over pounds of analyses and commentary to identify our most pressing concerns—the changes to the IEP process, discipline provisions, and local/state school system accountability, particularly in tracking expenditures and outcomes for "early intervening services."

A Tennessee contingent trekked to Atlanta—no easy task, given our 24/7 responsibilities as parents of kids with disabilities—for the first public hearing to offer comment on these and other issues. We asked for clarification, elucidation and the assurance that effective accountability frameworks would be put in place.

Our statements were well-reasoned, based in the guiding principles of the law. What perhaps our brief pronouncements could not convey is how vitally and deeply these fine points of law matter in families' lives. The conversation around the DCE table has been passionate, distressed, angry, fearful—all of those emotions underscored by story after story from the real world, of families and advocates struggling with sometimes fiercely resistant systems to obtain the most fundamental of civil rights for our children—an appropriate public education in the least restrictive environment.

An analysis of the ream of draft regulations reveals that the document often merely reiterates the language of the statute, rather than providing the necessary clarification, further definition, or practical guidance in implementation. In preparing today's remarks, the temptation was great to simply offer a rerun of our previous comments, since the needs of our constituents have not changed since February.

Instead, we join with other advocacy organizations in articulating an overarching global concern: the proliferation of provisions which shift the balance of power and control away from families and IEP teams towards school systems, typically under the rubrics of paperwork reduction, decreasing regulatory burden and increasing flexibility. Flexibility is a friendly word when used in the context of an IEP team's work to develop an individually appropriate educational plan for a child. However, when served up to school systems which historically have never achieved compliance with IDEA—and sometimes have actively avoided implementation of even its explicit mandates—it's a terrifying concept. Neither does this sort of flexibility correlate with an increased focus on system accountability.

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We appreciate those instances in which the draft regs fulfill their intended purpose—of clarification, explanation and operationalizing how the law plays out in the school day. Examples include the statement that while transition planning isn't mandated until a student turns 16, an IEP team may determine it is appropriate to begin earlier; and the language recognizing that the results of IQ testing taken in isolation are unlikely to effectively guide instruction. In these instances, the draft rules place the locus of control and action squarely in the domain of the IEP team and its collaborative planning processes, just as the law intends.

However, to ensure that the rights of parents to be fully informed, to be involved as partners in decisions about their child's education and to appropriately access procedural safeguards and due process are maintained, we believe that a significant retooling of these draft regulations is necessary. A host of organizations and individuals stand ready to provide further informed input, based on the real world status of students with disabilities in this country. I will close with the same words I used in February: the education of America's students with disabilities is far too important to be subject to misinterpretation or confusion.

Although the provisions of IDEA 2004 became effective on July 1, 2005, the state and most local education agencies will still follow IDEA 97 until the final federal rules are released, possibly as early as December 2005. The exception appears to be in the area of discipline, where some systems are already using the more restrictive definitions and procedures for the Manifestation Determination Hearing.

DCE's critical areas of concern:

THE INDIVIDUALIZED EDUCATION PROGRAM:

- SHORT-TERM OBJECTIVES REQUIRED ONLY FOR "STUDENTS WITH THE MOST SIGNIFICANT COGNITIVE DISABILITIES"
- HOW PROGRESS IS REPORTED TO FAMILIES
- THE PROCESS OF "AMENDING" AN IEP, WHERE CHANGES CAN BE MADE WITHOUT CONVENING AN IEP MEETING
- CHANGE IN LANGUAGE FROM "REGULAR EDUCATION CLASSROOM" TO "REGULAR EDUCATION SETTING,"
- IEP ATTENDANCE—FAMILIES CAN BE ASKED TO "EXCUSE" A MEMBER(S) OF THE TEAM

DISCIPLINE AND STAY PUT:

- MANIFESTATION DETERMINATION—FAMILIES MAY BE REQUIRED TO BEAR THE BURDEN OF PROOF AS WHETHER THE STUDENT'S DISABILITY "CAUSED" THE BEHAVIOR
- SUSPENSIONS FOR VIOLATION OF THE SCHOOL CODE OF CONDUCT

EARLY INTERVENING/RESPONSE TO INTERVENTION:

- A DISCREPANCY BETWEEN IQ AND PERFORMANCE IS NO LONGER REQUIRED FOR ELIGIBILITY UNDER LEARNING DISABILITY, BUT THE ALTERNATE PROCESS, RESPONSE TO INTERVENTION, IS NOT WELL DEFINED IN TERMS OF TIMELINES, ACCOUNTABILITY OR ITS USE IN CULTURALLY DIVERSE POPULATIONS

DUE PROCESS:

- A MANDATORY "RESOLUTION SESSION" MUST OCCUR WHEN A FAMILY (OR SCHOOL) HAS FILED FOR DUE PROCESS, BUT THE PROTOCOL AND PROCEDURES FOR THIS MEETING ARE NOT CLEARLY DEFINED.

If you are interested in more detailed information about IDEA 2004, please contact Holly Lu at hlu1055@comcast.net.

TENNESSEE PROTECTION & ADVOCACY, INC. BECOMES DISABILITY LAW & ADVOCACY CENTER OF TENNESSEE—NEW NAME, SAME MISSION



This fall Tennessee Protection & Advocacy, Inc. officially became the Disability Law & Advocacy Center of Tennessee (DLAC). Although the name has changed, the mission of the agency along with the advocacy and legal services the agency provides for persons with disabilities across the State will remain the same.

"It's time that our name adequately reflects the services we provide and the community that we serve," says Shirley Shea, DLAC executive director. "Far too often there was confusion over what kind of organization we were, and we hope this name change will help define our role in the community. We also hope that having a name that describes what we do will encourage people who could utilize and benefit from our services to contact us."

Along with the name change, DLAC unveiled a new Web site. The Web site can be found at www.dlactn.org. For further information or to contact DLAC about their services, please call 1-800-342-1660 or TTY 1-888-852-2852.

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BG: How might families benefit from your project?

JW: Educating and encouraging parents and students to become actively involved in the transition process is a goal. Workshops on the transition process are available and we provide individual technical assistance to parents and attend IEP meetings, if necessary, to ensure students receive appropriate transition planning and services.

BG: Do you have any short or long-range goals that reach beyond your current activities?

JW: Yes. Moving transition planning toward quality programming and services for all students with disabilities and producing technical assistance manuals and one page briefs for school districts to share with parents and students at or prior to the IEP Team Meeting. I would like to see more active and meaningful participation of students at their own IEP meeting including, when appropriate, directing the meeting.

I'd like to develop a Web site for students, parents and professionals to share information, assessment instruments, including student self-assessment, career searches, resource listings, etc. I also want to work more closely with college and university offices of disability services and with school counselors statewide, collect post-school outcome data statewide to drive program improvement efforts, and lobby for self-determination/self advocacy curricula in every school, either as a stand alone component or embedded in other classes.

BG: What one thing should students and family members know about the transition process?

JW: Students and families should know what the student will do the first day after exiting from high school. Where will they live, be employed, be involved in their community, participate in recreation and leisure activities, enjoy a social network or receive adult services for further education and training? Get on waiting lists, apply for services, and learn about the transition process to facilitate your being an active and informed member of the IEP Team.

Encourage independence whenever and wherever appropriate, teach independent living skills and inquire of the IEP Team how you may support transition services and activities. The school cannot and should not be responsible for all aspects of transition planning. The IDEIA considers transition planning as a "coordinated set of activities designed to promote movement from school to post-school". Coordinate with vocational education, guidance counseling, adult services, community employment and recreation opportunities, and family members to provide the experiences the student needs to prepare for adult living.

For more information, readers may contact Jane Winstead by mail at Director of Transition Services, Tennessee Department of Education, Division of Special Education, 2763 Island Home Blvd. Knoxville, TN 37920; by phone at 865-594-5691; or by e-mail at jane.winstead@state.tn.us.

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THE TENNESSEE COUNCIL ON DEVELOPMENTAL DISABILITIES: JANE WINSTEAD

IN MEMORIAM: LORI SIEGAL

I met Lori Siegal through my daughter, Laurie Hobson. You see, they both have Down syndrome. One day I was driving Lori home and my Laurie told her she hated having Down syndrome. Her friend, Lori, told her she used to feel that way, but not anymore. She told her how she loved who she was and that it didn't matter that she had Down syndrome. She told her how she wanted to advocate for people with Down syndrome and with disabilities to let the world know that it was okay and that they were just people, too. I decided that day that Lori would be such an asset as a self advocate to the board of directors of our local Down syndrome support group...and she was! Not only that, she went on to get elected as a self-advocate on the Board of the National Down Syndrome Congress. I miss that Lori won't be advocating for people with disabilities, but most of all I miss her as my friend.

- Martine Hobson, Board Member, Down Syndrome Association of Memphis & the Mid-South and Board Member, National Down Syndrome Congress

I lost my best friend, Lori Siegal. We both have Down syndrome. That is why we met, but we were best friends for other reasons. We liked to spend the night together. We both liked movies and pizza. Lori liked pepperoni best.

Once we took a trip to UT to cheer on the football team. They even had fireworks. We had a secret handshake we used every time we saw each other. It was cool.

Lori liked to call me M&M girl because I like M&Ms and I called her drama queen. We both liked boys and I will never forget the fun we had together. She will always be my best friend.

- Laurie Hobson is a Youth Leader Forum Graduate



LORI SIEGAL (LEFT) AND LAURIE HOBSON.

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